

‘Living together with dementia’ – Conceptual validation of training programme for family caregivers: Innovative practice

Dementia

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Abstract

This article presents results from a conceptual validation of the programme ‘Living Together with Dementia’, through an e-Delphi study carried out during April/May, 2015 with 26 Portuguese and Spanish experts. The programme consists of seven individual weekly sessions and two group sessions over a seven-week period. It covers dementia, communication and behaviour; demands and expectations of the caregiver role; basic activities of daily living; coping and problem solving strategies; physical and mental health of the caregiver and community support. The programme methods mainly consist of discussion sessions, practical examples/simulations and skill training.

Keywords

family caregivers, dementia, training programmes, psycho-education

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Introduction

The World Health Organization (2012) has defined dementia as a public health problem. This makes it necessary to consider the impact of dementia on communities and families, since they are central to the support of people with dementia. There are a great number of people directly or indirectly affected by dementia, which therefore makes it an overriding priority for all health professionals.

Family caregivers are a privileged care partner, since they enhance the interventions of health professionals and ensure their continuity. They also have a fundamental role in encouraging and supporting the person with dementia in his or her daily needs. Caregivers need support to improve the care provided to relatives with dementia. According to Alzheimer's Disease International (2012), there is a fundamental requirement to educate and support caregivers and improve quality of life for people with dementia in their own homes.

It is crucial to foster resources to support the family caregivers of people with dementia (Silva, 2009). The development of intervention programmes designed to assist family caregivers of people with dementia is of utmost importance, since with appropriate access to information, counselling and support, they can be helped to be better prepared for their caregiving role (Silva, 2009) and will be able to develop strategies to assist their family members with dementia (Leite, Menezes, Lyra, & Araújo, 2014).

According to Leite et al. (2014), there are several ways to educate and provide support to family caregivers. Notwithstanding the different approaches, the secret seems to be in adapting programmes to the specific needs of each family caregiver, his or her schedules and habits. However it is still necessary to create a framework for these approaches regarding their structure, duration and contents.

The present study was developed on the basis of these assumptions, following two previous ones that aimed at identifying the main features of a training programme for family caregivers of people with dementia living at home through an integrative review of literature (Sousa, Sequeira, Ferré-Grau, Neves, & Fortuño, 2016a) and afterwards with resource to focus groups (Sousa, Sequeira, Ferré-Grau, Neves, & Fortuño, 2016b). After the identification of these features, the 'Living together with dementia' training programme proposal for family caregivers of the person with dementia living at home was developed – and the concept validated through the e-Delphi technique. This programme has been designed to be flexible, in which it could be implemented both in caregivers' homes and in other community and care settings.

Methods

This was a one round e-Delphi study developed according to the five steps described by Justo (2005):

1. Composition of an expert panel using the following inclusion criteria: being a nurse and having at least three years of professional experience with family caregivers of people with dementia. The identification of experts was carried out by via email with representatives of health and teaching institutions as well as representatives of Portuguese and Spanish non-governmental institutions that deliver care to older people with dementia and their

family members. Fifty-four experts were identified (34 Portuguese and 20 Spaniards), between April and May 2015.

2. Finalising the number of participants: of the 54 identified experts, 26 responded to the online questionnaire (15 Portuguese and 11 Spaniards).
3. Formulation of the questionnaire: Details of the programme 'Living together with dementia' were converted into an online questionnaire through *Google docs*. After an introduction describing the framework and study aims, the survey collected data about the experts' social and demographic characteristics. Next, the experts were asked to consider the duration and type of programme; its objectives; themes and methodologies used for each individual and group; assessment periods and instruments. The experts were to mark their agreement regarding each of the items by means of a five-item Likert-type scale ranging from 'entirely disagree' to 'totally agree'. Two versions of the online questionnaire were produced, one in Portuguese and the other in Spanish which were sent via email from June 2015 onwards. The closing date for replies was November 2015.
4. Consensus formation process: for this work, consensus criteria were established, on the basis of the positive agreement level of the experts' answers to each item of the questionnaire. In this manner, positive agreement was defined as a rate equal to or above 50% (Scarparo et al., 2012), with positive agreement defined by the sum of the percentage of answers 'agree' and 'totally agree'. For positive agreement, three levels of consensus were established (perfect – positive agreement = 100%; strong – $70\% \leq \text{positive agreement} < 100\%$ and moderate – $50\% \leq \text{positive agreement} < 70\%$). Since in this study, positive agreement was achieved directly in the first round, we proceeded with the presentation and analysis of the results.
5. Statistical processing of the answers: analysis of the answers has been performed by means of descriptive statistics, namely distribution of frequencies (absolute and relative frequency) and measures of central tendency (median) with the use of the *Microsoft Excel 2013* programme and data analysis operative system *Google docs*.

Throughout the e-Delphi study, all ethical principles were adhered to: all 26 experts (100%) stated beforehand that their participation in the study was free and informed. They were briefed on the anonymity and confidentiality of their answers. They were also assured that the answers would only be used for research and scientific knowledge dissemination.

Results and discussion

Participant characteristics

Regarding the social and demographic characterisation of the experts who participated in the e-Delphi study, their average age was 43 years old and their average years of professional experience with family caregivers of people with dementia were 12 years. Table 1 presents the sociodemographic characteristics of the experts consulted for the study.

Suggested inclusion criteria

The programme 'Living together with Dementia' proposes five inclusion criteria for the family caregivers of people with dementia, which were widely accepted by the experts:

Table 1. Sociodemographic characteristics of the experts who participated in the e-Delphi study.

Variable	Number (%)
Gender	Female – 14 (54%) Male – 12 (46%)
Specialization in nursing	No – 4 (15%) Yes – 22 (85%)
Area of professional practice	Mental health – 14 (54%)
	Community – 3 (12%)
	Others – 5 (19%)
	Hospital – 9 (35%)
Country	Community – 8 (31%)
	Others – 9 (35%)
	Portugal – 15 (58%)
	Spain – 11 (42%)

Being the main caregiver of the person with dementia (89% – strong consensus); being able to read and to write (62% – moderate consensus); motivation to participate in the programme (100% – perfect consensus); caring for a person with dementia in the initial or moderate stages (54% – moderate consensus) and the person with dementia does not have a coexisting mental health problem (62% – moderate consensus). The inclusion criteria validated by the experts are congruent with the ones used in several studies in the field, such as Chien and Lee (2010), Judge, Yarry, and Orsulic-Jeras (2009) and Judge et al. (2009).

Psycho-educational approach

This programme aims to adopt a psycho-educational approach, with an overall aim of enabling individuals to undertake their role as a family caregiver. A psycho-educational programme seeks to help family caregivers to gather a set of behavioural and cognitive skills and thus deal with difficulties and stress, utilising a structured format (Gallagher-Thompson et al., 2012). This approach was chosen following the positive results from other psycho-educational interventions in terms of reductions in carer stress and depression and increases in knowledge and skills in caring for someone with dementia. All the experts agreed with this approach (100% consensus).

Programme length and frequency

The proposed programme has a seven-week duration and is composed of seven individual sessions and two group sessions. Individual sessions should preferably take place on a weekly basis, according to the availability of the participants and should not last longer than an hour. This suggestion achieved a strong expert consensus (73%). The timing of the two group sessions could be flexible, depending on the evaluation of the health professional and the caregivers' availability and will. Groups should not include more than 10 participants, should last no longer than an hour and a half, and the group should have homogeneous features (77% – strong consensus). These criteria are in accordance with the findings reported by other researchers (e.g. Gallagher-Thompson et al., 2012). An important aspect

should be ongoing support to the family caregivers after the end of the training programme. Group meetings should continue after the end of the programme so as to promote interaction and leisure activities among family caregivers (89% – strong consensus).

Initial evaluation

An initial evaluation of both the family caregiver and the person with dementia should occur the week before the beginning of the programme (73% – strong consensus). The evaluation of the family caregiver should be composed of three parts: socio-demographic evaluation (92% – strong consensus), application of evaluation tools (96% – strong consensus) and choosing the five most important needs for the family caregiver by means of a list previously made available (81% – strong consensus). The validated instruments for the evaluation of the family caregiver are the Scale of Caregiver Burden (Sequeira, 2007), composed of 22 items which seek to identify the objective and subjective burden of the caregiver, the Caregiver Assessment of Difficulties (CADI) (Brito, 2000; Sequeira, 2007), an index composed by 30 potential difficulties related with providing care to the elderly person, and the Caregiver Assessment of Satisfaction Index – Caregivers' Satisfaction Evaluation Index (CASI) (Brito, 2000; Sequeira, 2007), composed of 30 items related to positive aspects associated with the performance of the caregiver. All these tools gathered the experts' strong consensus. The final evaluation should take place the week after the end of the programme (85% – strong consensus) and the follow up occurs three to six months after the end of the programme (92% – strong consensus).

Session themes

To train the family caregiver in his or her daily tasks, a set of themes to be addressed throughout the seven individual and two group sessions were established (Table 2).

Suggestions about programme content accord with an existing consensus, namely Leite et al. (2014), Silva (2009), Santos, Sousa, Brasil, and Dourado (2011), Chien and Lee (2010) and Judge et al. (2009).

Although the programme 'Living together with Dementia' endeavours to cover the most important topics that might answer the needs of family caregivers of people with dementia, other topics might also be covered in the individual sessions with caregivers. What we intend is to train the caregiver to perform their daily tasks and endow them with knowledge and abilities; the organisation of themes during the sessions is thus more an orientation guide than a rigid catalogue for the health professional.

In terms of the proposed format for the sessions with the family caregivers (Table 3), we sought a diverse approach, as combined approaches seem to be more efficacious than information only groups (Santos et al., 2011).

For the proposed programme, we suggest utilising a range of eclectic techniques, since the combination of different approaches such as exhibitions, relaxation and discussion can significantly improve depression and anxiety symptoms (Santos et al., 2011), whereas information only programmes can increase anxiety (Santos et al., 2011). Programmes directed at family caregivers of people with dementia should also include skills training so as to optimise promote improvement in care giving and include problem resolution and relaxation techniques (Silva, 2009).

Table 4 displays a summary of the main features of the training programme for family caregivers of people with dementia living at home – 'Living together with Dementia'.

Table 2. Experts' views of programme content.

Individual sessions	Themes	Number of answers (%)/ Levels of consensus
First	What is dementia.	26 (100%)/Perfect consensus
	Stages and expected changes in each stage.	25 (96%)/Strong consensus
	Behavioral and psychological changes associated with the disease.	26 (100%)/Perfect consensus
	Therapeutic intervention	25 (96%)/Strong consensus
	Communication management strategies.	25 (96%)/Strong consensus
Second	Behaviour management strategies.	25 (96%)/Strong consensus
	Emotions and feelings associated with care.	26 (100%)/Perfect consensus
	Requirements of the role of caregiver.	26 (100%)/Perfect consensus
	Expectations for the future of the caregiver and the person with dementia.	26 (100%)/Perfect consensus
Third	Difficulty of the person with dementia in basic activities of daily living.	26 (100%)/Perfect consensus
	Strategies to supervise/assist the person with dementia in basic activities of daily living.	26 (100%)/Perfect consensus
	Difficulty of the person with dementia in instrumental activities of daily living.	26 (100%)/Perfect consensus
	Strategies to supervise/assist the person with dementia in instrumental activities of daily living.	26 (100%)/Perfect consensus
Fourth	Importance of cognitive stimulation in people with dementia.	25 (96%)/Strong consensus
	General strategies of cognitive stimulation.	25 (96%)/Strong consensus
	Environmental management at home.	22 (85%)/Strong consensus
	Security rules.	24 (92%)/Strong consensus
Fifth	Prevention of falls.	26 (100%) Perfect consensus
	Identification of coping strategies with the family caregiver.	26 (100%) Perfect consensus
	Train the use of coping strategies.	26 (100%) Perfect consensus
	Identification of key issues related to the role of caregiver.	26 (100%) Perfect consensus
	Identification of situations that cause conflict.	26 (100%) Perfect consensus
Sixth	Identification of possible solutions.	26 (100%) Perfect consensus
	Establish priorities.	26 (100%) Perfect consensus
	Importance of keeping physical and mental health.	26 (100%) Perfect consensus
	Identification of physical and relaxing activities that the caregiver can perform at home.	26 (100%) Perfect consensus
	Instructing and training relaxation techniques.	25 (96%)/Strong consensus
Seventh	Identification of relational problems associated with care-giving role	25 (96%)/Strong consensus
	Training strategies for managing relationships.	25 (96%)/Strong consensus
	Inform about existing resources in the community and on their functions.	26 (100%) Perfect consensus
	Inform about how to access each of the community services.	26 (100%) Perfect consensus
Group sessions	Matters	Number of answers (%)/ Levels of consensus
Two sessions	Challenges of the family caregiver role.	26 (100%) Perfect consensus
	Emotions associated with the caregiving role.	26 (100%) Perfect consensus
	Expectations for the future.	26 (100%) Perfect consensus
	Strategies to overcome the difficulties experienced.	26 (100%) Perfect consensus

Table 3. Programme methods.

Methods	Individual sessions	Number of answers (%)/ levels of consensus
Theoretical presentation of the topics	In all individual sessions	24 (92%)/Strong consensus
Discussion topics	In all individual sessions	25 (96%)/Strong consensus
Practical exemples/demonstrations	First session	25 (96%)/Strong consensus
Skills training	Third and fourth sessions	26 (100%) Perfect consensus
Practical exercises	Third, fourth, fifth, sixth and seventh sessions	26 (100%) Perfect consensus
Didactic videos	Third session	23 (89%)/Strong consensus
Group share	Group sessions	26 (100%) Perfect consensus

Table 4. Summary of the programme characteristics ('Living together with Dementia').

Programme characteristics	<p>Psychoeducational intervention for family caregivers of people with dementia living at home.</p> <p>Can be conducted in various contexts (home, hospital, etc.).</p> <p>Duration of seven weeks.</p> <p>Seven individual and weekly sessions with the family caregiver, lasting 60 minutes each.</p> <p>Two group sessions with family caregivers, lasting 90 minutes each, to be held in the weeks that health professionals and caregivers determine.</p>
Assessment moments	Initial evaluation before the programme, the final evaluation after the programme and follow up of three to six months with data collection instrument built for this purpose.
Individual sessions	
First	<p>Themes: dementia, communication and behaviour</p> <p>Methods: theoretical presentation; discussion topics and practical examples/demonstrations</p>
Second	<p>Themes: emotions, demands and caregiver role expectations</p> <p>Methods: theoretical presentation and discussion topics</p>
Third	<p>Themes: basic and instrumental activities of daily living</p> <p>Methods: theoretical presentation, discussion topics, skills training, practical exercises and didactic videos</p>
Fourth	<p>Themes: general cognitive stimulation and environmental management</p> <p>Methods: theoretical presentation, discussion topics, skills training and practical exercises</p>
Fifth	<p>Themes: coping strategies and problem-solving</p> <p>Methods: theoretical presentation, discussion topics and practical exercises</p>
Sixth	<p>Themes: physical and mental health of the caregiver</p> <p>Methods: theoretical presentation, discussion topics and practical exercises</p>
Seventh	<p>Themes: relationship management and community resources</p> <p>Methods: theoretical presentation, discussion topics and practical exercises</p>
Group sessions	
Two sessions	<p>Themes: emotions and expectations of the caregiver and sharing strategies</p> <p>Methods: discussion topics and group share</p>

Conclusion

The construction and validation of training programmes for family caregivers of people with dementia are essential with rises in the numbers of people with dementia and the high number of family members who undertake the role of caregiver. Training family caregivers means providing them with the knowledge and skills that allow them to provide better care to the person with dementia in everyday living. In this respect, psycho-educational programmes are the ones that seem to achieve better results, since, through a pre-defined structure, they explore and train a set of strategies which assist the caregiver in a better management of the cares provided to the person with dementia.

The programme 'Living together with Dementia', validated in the e-Delphi study developed, fits in a psycho-educational approach and, throughout a period of seven individual sessions and two group sessions through a period of seven weeks, aims at granting family caregivers the knowledge and skills to provide care to the family member with dementia. It explores a set of themes and utilises a range of methods that seek to give answer to the several needs and difficulties faced by these caregivers.

The programme was presented and validated by the experts immediately in the first round of the e-Delphi study, which can be justified by the methodology that was used for its construction, since it is the result of the findings of an integrative revision of other programmes and focus groups in the field about the features to include in programmes of this kind which explains the consensus of structure and content.

This programme could become an important tool for health professionals who assist the family caregivers of people with dementia. The next phase of our research work will be the experimental validation through a randomized controlled trial's protocol and the development of a short-term efficacy study.

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